

41 Stories & Tips On Telling Kids About MS



I am one of Stan's 3300 MySpace Friends (We call them Angels) We've given 78,400 Hugs of Support & Tips to MS patients on Stan's Blog. Look inside to see a few of them.



352,388  **myspace** **READERS**



After school Friday, I just kind of sat down and had a little talk with my son and told him the doctors finally knew what was causing my seizures.

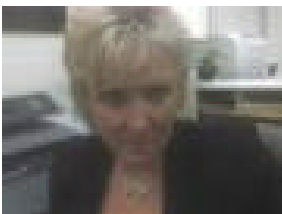
I told him it was Multiple Sclerosis.

And, instead of him getting more scared like I had expected, he seemed so relieved to finally have an answer. He was not happy that I could not promise him a cure, or that I could not promise him I would never have another seizure but he did definitely seem to feel better.

I feel so relieved now that I have told him! Becky



Don't think there is a book on how to talk to kids, would be nice maybe it would help us understand it more as this is a disease that seems everyday comes up with new symptoms, new pains for us, you name it. But I would just tell him that he was a brave little man for calling 911 and thank him for knowing how. And that you have a medical condition called MS. And tell him what you have found out about MS. I found out keeping family, and friends in the dark is the worst thing anyone can do so dear your son needs to be told right away, and just also I reminded my family this (I may have this awful disease but I in my strength and power going to go and do as much as I can, when I can even if there are days I have to drag, and I do and what I do isn't a good thing I go, and go, until I have to collapse and fall in bed and sleep for 24 hrs straight. But just sit him down and tell him and then give him a chance to ask you questions. Or go on the website together and look at the information even maybe he can chat with one of us on here if he has a question. I know I would try to help. Angie



There are books available for kids who have parents with chronic illnesses. Kids are aware and understand more than we give them credit for. I think you can explain to him that you don't feel good sometimes but that he should not be scared. He will handle your MS as long as you can handle your MS. Try to assure him that you will be alright and that you're still his mother and will be there for him but that some days you need to take a nap, and etc. Also when explaining things to kids, talk to them in terms they understand and provide just enough information in smaller doses rather than overwhelming them with all of it at once. Bottom line, he wants to know that you'll be alright. Show him lots of love. Much love and hugs to you and your precious family. We'll all here for each other. ~Shirley



I KNOW THAT IT IS HARD TO EXPLAIN TO OUR CHILDREN WHAT IS GOING ON, AND THEY TAKE WHAT THEY CAN COMPREHEND AND THE REST IS HARD TO EXPLAIN. THE MS SOCIETY, AND THEY ARE IN EVERY STATE AND CITY, HAVE REALLY GOOD BOOKS THAT CHILDREN CAN UNDERSTAND AND IT HAS PICTURES THAT EXPLAIN IT ON THEIR LEVEL, IT WILL HELP HIM WITH HIS FEARS. WITH MY SON, I LET HIM GO TO MY APPOINTMENTS SO THAT HE CAN ASK QUESTIONS, AND I DON'T HIDE ANYTHING FROM HIM, THAT WAY HE KNOWS WHAT IS GOING ON AND CAN GET IT FROM

A DR. THERE IS SO MUCH INFO AT THE MS SOCIETY, JUST LET THEM KNOW WHAT YOU ARE LOOKING FOR. YOU ARE IN MY THOUGHTS. MANY HUGS. TINA.



I'm not a MOM but do know that the MS Society puts out a magazine just for kids called "Keep S'myelin " You can call them at 1-800-344-4867 or go to their website at <http://www.nationalmssociety.org>. You can ask for free copies but they are also online in interactive (FLASH) version. Especially for children whose parents have MS. I hope this helps some. xo Kimberly in PA



Your son did a great thing when he called 911. He needs to know that coming from you. I am very proud of him. Ok, I had to tell my 3 kids about it when they were 3, 5, and 8. So you're already a little bit ahead of me. But it's basically gonna be the same. You said you already explained the other, so use the same tactics to explain MS. Only this time, tell him that the doctors know more about what is doing this, and it will help them help you get better or manage it more. "Mommy is sick with another disease that is almost like epilepsy, but has a few different things that are

different. Mommy doesn't understand it herself, so we can learn about it together if you want to. I could use the support from you, and you can use the support from me." And try to include him in your learning process sweetie. If you can explain epilepsy to him, than MS shouldn't be too much harder. The main thing to tell him is that the Doctors are trying to help you. That will reassure him that they are doing good for you. Know that you are in my thoughts and prayers.

~~~~~BE SAFE, BE STRONG Bubba



It is so hard trying to explain something that we don't understand. My children were joking that they are smarter than I am while we were doing homework. I know at 2, 4, 9,&10 they don't understand. So I decided that we will all learn about it together. The first thing that I stressed with them is that I'm not going to die from MS.

It put their minds at ease and we take it day by day. It's something that hopefully will just make us stronger and appreciate little things. Good luck and I hope you and your son get through this stronger than ever!! You'll be in my prayers. Kerry



There are books for children to help explain MS etc. If you contact your local MS chapter I'm sure they could give you some helpful things. When I was first dxed I wasn't that young but young enough to be fairly ignorant about this thing and they sent me a little comic book like explanation it's served well over time and I still have it as a primer for new people dealing with it with me or whatever... The NMSS as Keep S'Myelin for kids etc...

You could tell your son you don't have "epilepsy" your seizures are due to something else... let him know that research for THIS illness is really good these days and there may even be a chance you could be cured one day! Do it in a positive way. Let him know no one has anything promised in this life as to how things will go day to day or for a lifetime... that you both are lucky for many reasons, MS is just one of those things given to be dealt with, it doesn't have to be all bad it can make a family stronger! Tell him you can do walks together raising money to beat the thing etc... Be positive about it and it will be less scary for him & you ;)



I was dxed in '03 and I have 3 kiddies--9, 6 and 3. My 9 yr old is the one who saw me "before" MS and has experienced me being "not well", whereas the younger kids don't really know the difference between "well Mommy" and "not well Mommy". Once I embraced MS, I got much support with my local MS chapter. On top of sending me MUCH info, they subscribed my kids to "Keep Smilin", the quarterly newsletter for kids. They also sent 2 books for kids, "My Mommy has MS" and there is another one--I cant remember the name of it--sorry!! Also, if you go to David Lander's site (you know, "Squiggy" from "Laverne and Shirley" fame), he produced a DVD for kids. I rented it from the MS Library with my local chapter.

Please contact your local chapter--they are a HUGE resource especially if you have kids. I was always able to get info for me but really for my kids. My son (the 3 yr old) doesn't understand yet, but my girls (the 9 and 6 yr old) get it. They really do and understand. Yes, they are still kids and forget my limitations, but kids are so resilient. They understand that Mommy is going to be okay as long as she follows the Dr.'s instructions. Becky!!!!!!



I'm Julie. I am also a mom, my kids are now 14 and 16, but were 8 and 10 when I was dx. I feel your pain.... It is hard to sit down and tell them what is going on. I did a lot of research online on how to tell children, and found some great information on the MS Society web site, and now I have a book MS For Dummies, (yup, real book) It has an entire chapter dedicated to telling your children, as well as keeping them in the loop. It was hard for my kids to understand at first, but the older they get they understand more, and help more. I think it has actually brought my kids and I closer together. **** HUGS **** Julie



I know it's hard and I'm sorry. I have 3 kids under 7 so I get it. The MSAA and NMMS have great books and videos for your son to help him understand. Go to msaa.com and the NMMS....they have all kinds of stuff including a little news letter (my son's just came today) called Keep Smillin'. It's a little newsletter that helps explain things. Hopefully this will help you. Good luck. (((Hugs))) Superwoman



You've come to the right place for support * Kudos to your son for knowing to call 911 *

Most 9yr olds that I've tutored can understand something better when there's a visual demonstration and you're probably wondering "How the heck do I demonstrate the sclerosis process of a neuron??" Well... I've found that this following example can be helpful in explaining why you're having the symptoms.

I've taken an old lamp electric cord (or an old extension cord) and show what a neuron might look like with its insulation in tact then take out a cord with its insulation stripped and show how damaged it's become. I then ask the student if they think the lamp would be able to turn on with a damaged cord (wires exposed and cut in some sections) or will the insulated cord work better?

I wouldn't recommend plugging in the damaged cord of course but a 9 year old can tell which cord is damaged and how it affects the lamp's performance.

Our brains are like a circuit board that controls many things and if one section is affected with MS - it can really throw our body off and cause them to "short circuit" (epilepsy). Take care my fellow "MS Warrior," jb



I also have a two young children, and last year when I was told possible MS I told my at the time 9 year old daughter that they thought I had a disease that makes me tired all the time and sometimes I can't feel my legs. And then I printed a sheet off the nmss about ? kids have about MS. I let her read it on her time. Then I asked her did that answer all her fears and questions. She said yes I was wondering if it was contagious and will I get MS when I grow up. So we shared lots of tears and hugs.

And for my 4 year old I didn't really get into a lot about MS, but he knows something's wrong with mommy, and he knows that the problem is in my brain. so when I'm having a really bad day he says mommy is your brain making u do this. I hope this helps u with this very hard subject. I know But I promise he will get it and kids deal with this in different ways. Alyson



I run into the same problem with my boys. I try to answer their questions as honestly and make it as simple as possible so they understand. Try contacting your local MS chapter. Down here in Central Florida they do a lot of kid based groups, where they teach them about MS and they also do a great camp for a week. They talk to the kids about MS in kid language. My boys have come home enlightened and love the camp especially, since they're around other kids whose caretakers have MS and they see they are not the only kids who's parents are sick



As for your children, when I had my son I was so worried about what he would ask, how I would explain, etc.. He is now 12 and understands my disease more than most adults. And all I did was when something was not working right, I would try to explain what was wrong so that he could understand, and I also never hid anything from him. Treatment, falling, sleeping, I think trying to explain it to a level in which they understand, will help and as they get older they will. They have a great mom. You are in my thoughts. Many hugs. Tina



My kids were 10 and 15 when I was diagnosed and I think no matter their ages, it's hard either way to try and explain the "why's" and "what's", etc. What I did and found very helpful was to take them to the national ms foundations website - www.nationalmssociety.org and go to the page for kids, it's called Keep Smyelin. There you will find a booklet you can print, coloring pages, etc.. to read to your kids that does help to explain this horrid disease in more kid friendly terms. That's about all the advice I can give. I wish you the best of luck!! Sending big hugs, Sher



This is what I did for my at the time 9 year old daughter. I printed off some info on the nmss site, and let her read it, then after she's done I asked her if she had any questions. And of course she did. The first one was is it contagious? That one right there was NO. Then she said to me what a big relief. Then she asked will I get ms? This one was hard too, but I was frank with her, and told her that the researchers can't tell if it is or not.

But it's likely that u won't have ms when u grow up.

See being truthful, but not no much info can go along way. I also have a 5 year old son, and I just told him that mommy will have some days that she don't feel well, and I told him that there is something in my brain that causes this. SO now when I have a bad balance day, without saying anything to him, he says" aww, is it your brain making u do this". SO now he plays along with it and we all 3 make jokes about my brain. See u can make this a positive thing for u and your kids. Huggs, aly



I have a 4 year old, a 12 year old, and a 14 year old. My 14 year old has grown up with a close friend who has diabetes so she could understand it. The four year old will ask me every night if it is time for my shot- not because she likes to watch but because she gets to watch Piggly Winks! When I found out, my husband and I told the kids. I made sure that they understood that MS

was not going to kill me, but that I would have it for the rest of my life. No one else in my immediate family has MS, but a few in the extended part do. I have RRMS, and have not had a flare up since the one that got my dx. Some days I am a little tired and will take a nap, but the kids seem to have come to grips with it quicker than most adults. That's the things with kids, we don't give them enough credit. See if you can find a book on MS for kids. That they may be help to the 7 year old and you too! Hugs and kisses! :) Stacie



I have a 5 and 7 year old and they just know that mommy's legs don't work and it's because I have MS. I am secondary progressive, so that's my main symptom. Oh, they've also seen me wet myself... that's fun to explain to a kid – mommy's not potty trained. Oh, and then I pray they don't share it with the ex :o) (I hope that made you smile). Good luck. I'm always interested in

what everybody has to say on this topic. Good luck to you. ~jen

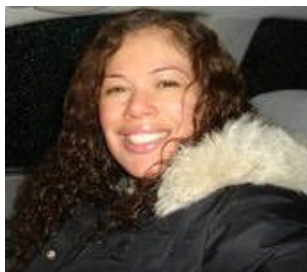


I have 3 boys...which are very intelligent, so I couldn't get away with just anything. They wanted to know how the MS affects the body. I used the example of an extension cord. Without the plastic coating, the wires can easily be broken or damaged. Just explain to them that our nerves are the same, and the MS just eats away the outer coating.

Also, if you are on Copaxone, the Shared Solutions center has a book on how to explain MS to your children. I haven't received the book as of yet, but should be getting it soon. If you message me, (to remind me) I will let you know how the book is when I get it. Be strong! Telling your children something is wrong with "Mommy" is never easy. But after explaining things to my boys and being honest, they are so much more understanding. They ask all the time how I am and if I need help with anything. Just be as honest as you can, children understand a lot more than we give them credit for. Many ((((((((((((((hugs)))))))))))))) to you and your family!! Rhonda



My son is 2 and I think he will be used to seeing my walker when he is older. Make sure that your kids know you are not gonna die and can live a very long time. Tell them MS affects the nerves. Imagine an electrical cord. The outside protects the wires on the inside. Without the protection the wires (nerves) cannot do its job. Then explain your symptoms. Good Luck to you. HUGS



It's hard for kids of all ages. Dana has some good advice above. You can also print out a copy of "My Mommy has Ms" here: <http://www.mssociety.ca/en/pdf/mommy.pdf> My 7 yr old has been very good but I know it's hard on her. She knows I have MS but sometimes she doesn't get it and gets sad. I don't think there is any easy way but talking and talking and talking helped me tremendously. Good Luck! (((HUGS)))



My kids have been the most understanding people in my life about my MS. I suppose it would be harder if I would have had a major exacerbation or mobility problems, but they are fully aware of my condition (I explained it like electrical wires losing their insulation) and my issues with fatigue, heat, and stress. I'm not really sure what to tell you because everyone's situation is different, but I think it's important to be as honest as possible. It doesn't have to be scary, just informative so they know what's going on. I'm sure you are more important to them than a day at the lake. My kids know that when we go to Busch Gardens or

something, we're only going for a few hours because that's all I can take. If they didn't know about the MS, they probably would throw a fit when I said it's time to leave! The NMSS has brochures that can help you explain specifically to children... <http://www.nationalmssociety.org/multimedia-library/brochures/for-children--teenagers/index.aspx> Good luck! *hugs* Posted by Kendra



I live in FL. and they have a camp for kids ages 5-13 and it helps the kids understand a little. It's a weekend thing and my twins have been 2 times. You should find out what is in your area.



I took the same approach as Bubba. I told my kids I'm not dying, but have a disease that may make me tired and all of the other symptoms. I told them I would be asking them to do more around the house and more frequently.

I tend to be extremely honest with my children. I would rather them hear it from me! Posted by Jessica



I also kinda took the same approach as Bubba, but I was diagnosed four and a half years before my daughter was born, so to her MS is "normal"...lol She had more questions when she started preschool and the other moms didn't use a cane, etc. She made me proud one afternoon when she told one little boy, "My mom's not weird, she has multiple sclerumpus!!" She was 3 1/2!!



You can and should speak to your children about your neurological condition. HERE'S HOW:

Kids don't miss much. Even if they're too young to understand everything about multiple sclerosis (MS), epilepsy, head injury, muscular dystrophy, or migraine headaches, you probably won't be able to hide it from them.

And there's no reason to. Experts and parents agree that openness is the best policy, at virtually every age.

Be Honest

It's usually not a good idea to try to hide your condition, no matter how difficult it may seem to tell your child about the diagnosis.

It may mean going outside the comfort zone of normal family conversation, says Kim Koch, director of family and support programs at the National Multiple Sclerosis Society. But for the family to function as a normal unit, kids need to learn about your disorder. It's going to be there for the long haul, so it's important to talk about it.

She says staying silent won't prevent kids from suspecting that something is amiss. Kids have creative imaginations, she says. They'll create diseases because they don't have a name for it. They'll come up with something worse.

Above all, don't lie. You can simplify things or leave details out according to your child's age, but don't tell them everything's fine, says Adam Bender, M.D., an associate clinical professor of neurology at Mount Sinai School of Medicine in New York, NY.

Pick the Right Moment

Pick a calm time and place for the conversation, and make sure your child isn't in the middle of homework or a video game or some other distraction. Arrange for your spouse or partner to be there for assistance and reassurance.

Choose a time when you're not in acute distress. For example, you won't be able to explain migraines patiently and clearly if you are suffering from a severe headache, says A. David Rothner, M.D., a pediatric neurologist at the Cleveland Clinic in Ohio.

Stay Calm

It's important to move beyond your own fears, says Dr. Bender. You need to feel comfortable, because children pick up on nonverbal messages very well, he says.

If you are particularly nervous about the conversation, contact the local chapter of a non-profit advocacy organization for your disorder, suggests Kim Koch of the National Multiple Sclerosis Society. Often, chapter representatives and volunteers can offer their expertise to help you develop a script for talking to your kids. Educational materials developed for children, such as the National Multiple Sclerosis Society's Keep S'myelin newsletter and Timmy's Journey, a cartoon about a young boy learning about his father's MS, can be helpful too.

Use Their Questions as Your Guide

Children will let you know what level of information they're ready for by the questions they ask. Don't discourage questions, and ask them whether there's anything else they want to know as you're finishing the conversations, says Dr. Bender.

If you pick up on the slightest bit of curiosity or concern, give them the opportunity to talk about it, he says. Let the child let you know about how much they're ready to hear.

To get the conversation started, you can ask them what they already know about your disorder, says Dr. Rothner. Like all of us, children sometimes have preconceived notions or fears that are far from reality. They may need to be reassured that migraines aren't fatal or that seizures will subside.

Don't Overwhelm Your Child

Your kids may need to understand why you tire easily or can't fix their toys. But they don't necessarily have to be in on the intricate details of medical procedures or know what their chances are of inheriting your neurological disorder, especially if symptoms are unlikely before they become teenagers or adults.

Koch advises parents to become well educated about their diagnosis, but they don't have to share everything about the disease with their children. Parents should not present the worse-case scenario, things like wheelchairs or hospitalization, which are very scary to kids, Koch advises. They shouldn't jump to extremes.

There's also no reason for children to know, for example, that they have a 50 percent chance of inheriting migraines from a parent. They'll be sitting around waiting for them to happen, Dr. Rothner says.

If children ask whether they will get headaches, you can tell them that it's possible, but emphasize that most children don't get migraines. Stay positive and reassuring, Dr. Rothner says.

Accentuate the Positive

Sharon Dodge, a Maryland mother with MS, celebrates advances in medical research and advocacy with her three children.

Even difficult images and incidents can have a positive aspect. Audrey Nelson, a mother in Eau Claire, WI, tells her children the long hairline scar she got from surgery following a traumatic brain injury is the place where the doctors put me together. Rob Roozeboom, who has limb girdle muscular dystrophy, regularly treats his children to rides on the motorized scooter he uses to get around.

Trust Your Child to Accept You

Roozeboom secretly feared that one day his children would be embarrassed to be seen with him because he wasn't a he-man, a superman-especially if he had to use a wheelchair. Then his five-year-old son Jager said to him, Daddy, if you end up in a wheelchair, can I ride with you?

I said, 'Buddy, you have no idea what that means to me, to know you love me for me,' Roozeboom remembers.

Parents are often surprised at how accepting kids are of their condition, says Jacqueline A. French, M.D., director of the clinical trials consortium at New York University's Comprehensive Epilepsy Center in New York, NY. I don't see many kids who don't want to be with their parents because of their disorder, Dr. French says. If I see anything, it's parents who complicate their relationship with their children by worrying about these things.

Prepare for Emergencies

Teach your children how to dial 911 in case of a medical emergency. Some children can master this skill as early as five, but the typical age is usually eight or nine.

Work with your children to develop an age-appropriate strategy in case of a seizure, fall, or other circumstance that may require medical attention. Make sure your children are not only capable of, but also comfortable with, performing the necessary tasks. If they aren't, develop a support system with trusted friends and neighbors who can step in if you're disabled.

Know that Kids Want to Help

The first time Roozeboom's son Jager helped him put his pants on in the morning, he had to choke back conflicted feelings about the role reversal. I thought, I'm supposed to be helping him, Roozeboom recalls.

Instead Roozeboom let Jager know how proud he was. I said, 'You did awesome! You did it better than mommy!' He was proud as a peacock.

Though Roozeboom wishes he didn't need the help, he sees the way helping benefits his son. It's good to see him know what it means to assist someone else, he says.

Dr. French says kids who grow up with parents who have a serious disorder tend to become responsible and very involved in their parents' care. She's seen these mini-nurses as young as age six.

They're often hyper-responsible before their time, Dr. French says. They call the office to ask why their mom's not doing well. They get very involved.

But avoid relying on your child too much, too soon. Even when children want to help, avoid shouldering them with adult-level responsibilities, such as giving shots, managing medication, or helping out on the toilet, says Koch. Hire help or look for other family members or friends who could fill that role, she advises.

Encourage Peer Support

Sharon Dodge's three children, ages nine through 13, have benefited enormously from attending Discovery Weekends run by the National Multiple Sclerosis Society. The weekends feature art therapy and other programs that encourage kids to express their feelings about their parents' MS. Most importantly, Dodge says, Kids get to socialize with other kids and talk about their common experiences.

Never Blame Your Child for Your Disorder

Most importantly, avoid outbursts like You stressed me out so much I had a seizure or You gave me a migraine. It's harmful to make kids feel they have a negative impact on your disorder, or to try to control them or make them feel guilty with your illness, says Dr. French.

Tips for Young Children

Keep It Simple

Preschool children may only need to know the most basic information: Daddy has trouble with his balance and needs to be careful here; Mommy has a headache and needs to rest.

Use age-appropriate explanations.

A common tactic parents with MS use to explain their illness is to wrap their finger in a blanket and tell their children that the finger is the nerve and the myelin is the blanket. They can remove some of the blanket to talk about the wearing away of the myelin coating on the nerve.

Take Age-appropriate Cautions

If you have epilepsy or another disorder that may leave you suddenly unaware of your surroundings, make sure you have someone else around to help with toddlers. It doesn't take long for them to wander off or get into something dangerous, Dr. French says.

Another precaution she recommends is to feed and change babies on the floor to prevent them from falling or being dropped.

Tips for Teens

Satisfy Their Curiosity

The teen years may bring more challenging questions. They'll learn genetics in high school biology, which may raise questions about their risk of getting what you have. Precocious children may ask about hereditary factors as early as nine or 10.

Again, use their inquiries as a signal that they're ready for the information. If you don't know their risk of getting your disorder, research the answer with your child.

Monitor Internet Use

Dodge's 13-year-old son looked up stem cell research on the Internet and stumbled upon Web sites generating rumors about researchers using aborted fetuses to collect stem cells. When he asked her about it, she took the opportunity to explain that though the Internet was a wonderful research tool, not every Web site is credible.

Be sure to encourage your Internet-savvy teens to ask you about anything they don't understand. Teach them how to identify reliable sources of information, and guide them to helpful Web sites (see Resource)